

Advancing the National Electronic Disease Surveillance System: An Essential Role for Public Health Laboratories





APHL Mission

To assure continuous improvement in the quality of laboratory practices in order to achieve a healthier world.

Who We Are

The Association of Public Health Laboratories (APHL) is a national, non-profit association dedicated to working with its members to actively promote the interests of public health laboratories.

By promoting strong programs and public policy, APHL works hard to ensure that public health laboratories have the resources and infrastructure they need to protect the health of U.S. residents and to prevent and control disease globally.

Advancing the National Electronic Disease Surveillance System:

*An Essential Role for Public Health
Laboratories*



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PREFACE

The Public Health Laboratories (PHLs) are enthusiastic to participate as active partners with CDC's National Electronic Disease Surveillance System (NEDSS) program, both as important stakeholders in the final system and as experts who can bring a unique, science-based perspective to the table.

Advancing NEDSS makes the case for active public health laboratory participation in NEDSS' design and implementation and highlights the many benefits that will ensue from increased PHL involvement. The authors especially hope that this document will augment collaboration between state PHLs and state epidemiologists, as well as other state NEDSS participants and that CDC will actively encourage these collaborations by acting on the recommendations of this document. Additionally, it is hoped that the partner organizations, including the Association of State and Territorial Health Officials (ASTHO), the Council of State and Territorial Epidemiologists (CSTE), the National Association of County and City Health Officials (NACCHO), the National Association of Health Data Organizations (NAHDO), and others will gain an understanding of the importance of a more active role of PHLs in implementing NEDSS.

Working together, the public health community can make tremendous strides toward fulfilling the broad vision of NEDSS: integration of public health and healthcare information systems. APHL and its constituents are committed to exactly this kind of broad partnership to achieve this vision.

However, the NEDSS initiative, particularly in its early stages, evolved quickly and without an explicit mechanism to assure the full and active involvement of the nation's public health laboratories. Consequently, that involvement has been severely limited, as reflected in a number of concerns voiced to APHL, and, needless to say, the process has suffered as a result. A misperception quickly developed that PHLs were somehow being excluded from participation in NEDSS' design and implementation. Unfortunately, circumstances bolstered this misperception. Participants at the first NEDSS stakeholders' meeting (March 2000) failed to disseminate NEDSS information to PHLs. Had APHL's direct communication link to PHLs been utilized, information on the NEDSS initiative could have been more widely disseminated before requests for funding applications were distributed to states in May. Most likely, the lack of coordinated dissemination of information during the two-month, lead-time created a general lack of awareness among PHLs of the availability of supplemental funds for NEDSS. The chosen funding process, the Epidemiology and Laboratory Capacity (ELC) and Emerging Infections Program (EIP) grant processes (see page 24), had the inadvertent effect of significantly limiting PHL participation since very few PHLs are listed as ELC and EIP contacts. Finally, NEDSS initially focused on electronic laboratory reporting pilot projects with private sector laboratories, which may have contributed to a misperception that NEDSS would include only private sector laboratory data. Clearly, the broad vision and scope of NEDSS had not been realized.

The CDC's response to these concerns has been forthright. The agency has clearly stated that PHLs are critical NEDSS partners, that PHL data is a critical component of disease surveillance, and that PHLs are significant players in data gathering. The CDC has emphasized to fiscal year 2001 ELC grantees the importance of collaborating with *all* relevant health department units, including

public health laboratories. Additionally, the NEDSS grant application specifically identifies public health laboratories in two areas: electronic data exchange and integration into “the planning, execution, and management of (NEDSS) activities.”

Hindsight can be instructive, but does not move the process forward in and of itself. It is critical that state PHL directors proactively seek involvement in the NEDSS process within their state health agencies. It is equally critical that the CDC specifically fund PHLs to engage in NEDSS-related activities and publicly encourage PHL participation in the NEDSS process at the state level. This document, in part, addresses the concerns voiced by PHLs. More importantly, it provides useful information about the NEDSS initiative from a PHL perspective.

EXECUTIVE SUMMARY

The goal of this document is to increase the participation of PHL directors and their associates in the National Electronic Disease Surveillance System (NEDSS). Participation to date has been minimal or totally lacking due to a number of different reasons explained in this document, but one of the most significant reasons is that laboratorians have not been highly visible in state or national activities related to surveillance and electronic reporting. Many state laboratories do not have the necessary equipment or personnel to effectively participate in these activities. To become more involved, laboratorians must document the important role of the laboratory and acquire sufficient working knowledge to become effective team members of state surveillance activities.

NEDSS is defined by the CDC as “a broad initiative to use data and information systems standards to advance the development of efficient, integrated, and interoperable surveillance systems.” In brief, it is a national surveillance initiative that capitalizes on information technology to electronically exchange data important to public health. The emphasis on national standards allows the scope of NEDSS to be broad and to eventually include both infectious and non-infectious diseases. Significantly, the use of the standards that NEDSS identifies will allow utilization of new data sources for public health surveillance, including clinical data, health care system information, and vital statistics.

Given the comprehensive nature of NEDSS, the Association of Public Health Laboratories (APHL) recognizes that PHL participation in the design and implementation of the system is critical for at least two reasons. First, PHLs create much of the data that the system will utilize. Second, PHL staff possess valuable, specialized knowledge that will lead to a stronger and more complete, nationally integrated information system.

State Public Health Laboratories:

- Account for a significant proportion of reportable disease testing (approximately 40 million specimens each year).
- Are key to the early recognition and confirmation of infectious diseases.
- Have frequently been the first to recognize unusual findings that have led to the discovery of infectious disease outbreaks and identification of mutational variants or antibiotic resistance isolates.
- Are the front-line laboratory where unusual diseases associated with bioterrorist activities will be evaluated.
- Perform specialized testing not available in the private sector.
- Have expertise in newborn testing, Lead poisoning prevention, blood alcohol, water quality, radiation, and environmental testing.

The overarching recommendation of this document is for APHL members to take advantage of these areas of synergy and actively help close the gap in PHL participation in NEDSS. This will not occur unless the CDC develops policy and mechanisms to enable laboratory participation. To this end, the Board of APHL recommends that a national meeting be convened in 2002 to identify the process needed to incorporate PHL information into NEDSS surveillance activities. Additionally, APHL recommends several immediate steps the CDC can take to reduce the current gap in PHL participation. The quicker state laboratories become full participants, the faster the national system will acquire the capability of moving beyond infectious diseases into bioterrorism response capability,

newborn and child health testing, lead testing, environmental sampling, radiation safety and water quality management, each of which fall within the scope and broad expertise of state PHLs.

THE NATIONAL ELECTRONIC DISEASE SURVEILLANCE SYSTEM (NEDSS)

An Opportunity for Public Health Laboratories

Imagine the world without generic credit cards, a world that required a separate store credit card for each and every merchant you patronize. If the business community had not agreed upon national standards for the content and structure of information carried on charge cards, this unwieldy situation would likely be reality. Thanks to common standards, however, your VISA®, Mastercard®, or American Express® card can not only be used at the drugstore, but also in the ATM machine, at the gas station, and in a dozen different grocery stores. Moreover, thanks again to those common standards, each month a cumulative summary of charges is assembled and sent to you automatically. Depending on your charge agreement, you might even get an annual statement summarizing every purchase you made throughout the year.

The public health community has been slow to take advantage of new information technology—yet, it is clear that future improvements in public health depend on the ability to capitalize on state-of-the-art information technologies. NEDSS is a coordinated effort to play catch-up. That is, to achieve the same seamless flow of public health data that the business community has achieved for commercial transactions. Using the retail analogy, under NEDSS a portion of a laboratory's "business product" becomes a public health transaction. The transaction must be recorded, and records transmitted to multiple locations inside and outside the state health department (SHD). Information about the transaction must also be maintained in a central repository so that it can be sorted into weekly, monthly, and/or yearly reports and made available to relevant customers. Just as credit cards facilitate out-of-state purchasing, NEDSS will facilitate public health transactions amongst state PHLs, private sector laboratories, and state programs, as well as CDC.

For the first time, NEDSS provides the opportunity to address information-age technology issues on a national level; issues such as the organization of a data repository, the use of standardized test codes, the uniformity of test reports, linkage to new data sets, and confidentiality.

PHLs produce, collect, store, and export the data that undergirds important public health programs. Obviously, it is essential that these data are incorporated into a state's NEDSS program. PHLs, through NEDSS, have the opportunity to review how their business is conducted, make technological upgrades, establish interoperability with surveillance and health information systems, and, significantly, participate with public health partners to address important information-age technology issues.

Immediately, NEDSS provides the opportunity to enhance interactions among the PHL, state epidemiologists, information technology units, and myriad program areas within the SHD. Without the active participation of these, as well as others in the SHD, the successful integration of public health data in NEDSS will not be realized. The need for collaboration has been recognized by CDC and has been partially addressed in the evaluation criteria for the 2001 NEDSS grant applications. Points were awarded to those applicants demonstrating that there is

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“a mechanism in place or planned for effective decision-making *across relevant units of the health department* (emphasis added).”¹

The Impetus for NEDSS

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Public health information exists in thousands of places: the record systems of public health agencies and grantees, the information systems of health care institutions, individual case reports, and the data files of various surveys and surveillance systems. Many existing information systems were developed with categorical funding in response to high priority data needs, and they have continued to evolve in ways that meet the needs of individual programs; for example, STD-MIS for sexually transmitted diseases, TIMS for tuberculosis, HARS for HIV/AIDS, PHLIS for foodborne and diarrheal diseases, and PulseNet for molecular subtyping of foodborne diseases. Consequently, the data has been collected in incompatible formats, making it extremely difficult to aggregate data to describe individuals, populations, communities, and public health related issues, or to analyze diseases for prevention and control. The development and ongoing evolution of these separate information/surveillance systems has resulted in a patchwork of data systems (sometimes referred to as “stovepipes,” “silos,” or “stand alones”), which, in turn, has led to duplication of effort, left critical information gaps, strained cooperative working relationships, and made it strikingly difficult to accomplish the mission of public health.

The National Electronic Disease Surveillance System, funded by the CDC, aims to modernize and enhance public health surveillance and information systems by electronically linking and integrating a wide variety of surveillance activities, thereby overcoming the problems of data fragmentation. When complete, NEDSS will incorporate an internet-based infrastructure for data accumulation to facilitate timely and accurate reporting, while at the same time increasing the ease with which disease information can be accessed, sorted, and analyzed for public health purposes.

NEDSS and the NEDSS Base System

NEDSS itself is not software, but a set of standards that provides a common approach to the storage and exchange of disease surveillance data. Specifically, NEDSS identifies national standards for data architecture, data transfer, and a user interface, as well as tools for data interpretation, analysis, and dissemination. In and of themselves, the NEDSS standards do not represent a complete solution. Rather, they are a blueprint from which standardized—and therefore interoperable—solutions can be designed.

Ultimately, NEDSS will offer users secure internet transmission, common reporting protocols, common data formats, and a common user interface. The implementation of NEDSS-identified standards depends upon the development of an information systems architecture with eight defined elements:

¹ Guidance for Fiscal Year 2001 Supplemental Funds for Epidemiology and Laboratory Capacity for Infectious Diseases (ELC) Cooperative Agreement. [ELC Supplement A – NEDSS FY2001: New Activities]. National Electronic Disease Surveillance System (NEDSS) Activities. The Centers for Disease Control and Prevention.

- A **browser-based** data entry and data management system to facilitate data reporting and exchange among local and state health agencies, commercial and public laboratories, and others.
- The ability to accept, route, and otherwise process electronic messages presented in **Health Level 7 (HL7) format** with laboratory, clinical, or public health content.
- An **integrated data repository (IDR)** that allows information from multiple state-based and CDC categorical programs to be accommodated, (using patient-centered information where appropriate), associates incoming data with existing data, supports data accumulated through various means, and is accessible by commercial software for reporting and analysis.

An active **data translation and exchange (integration broker)** function that supports data translation, data import and export, queuing, and messaging for bi-directional interchange of data. (This element facilitates the management of data from separate state information systems as if they were part of a single integrated system.)

- **Application server-based development** surrounding the data repository that will apply business rules and initiate integration broker activity.
- The ability to perform **selective data reporting** according to user need-to-know, conduct **statistical analyses** and **Geographic Information Systems** activities, and perform other mapping, display and visual functions.
- A standards-based, shareable **directory** of public health personnel.
- A **security system** with appropriate policies to safeguard sensitive data.

Although all of these elements are relevant to PHLs, some may have greater importance to individual laboratories. All laboratories, however, will find that electronic messaging is essential if they wish to participate in the future of public health. In this case, the NEDSS- identified standards are HL7 (the most widely used standard for the transmission of health-related data), LOINC (a standard vocabulary to identify laboratory test type), and SNOMED (a standard vocabulary to describe laboratory test results and other relevant information). Already many commercial laboratories and clinical systems transmit HL7 formatted messages, although the majority of public health laboratories in states and at the CDC do not. Public health laboratorians must work to build this capacity and to assure that the systems designed to process HL7 messages also meet the specific needs of PHLs. The NEDSS initiative offers entrée into this process.

Even though some states are choosing to develop their own systems using NEDSS standards, others have expressed interest in CDC-developed software that conforms to NEDSS standards and architectural elements. This request led to the development of the NEDSS base system. While NEDSS is *not* software, the **NEDSS Base System** is a combination of software, hardware and the necessary architecture to make it all work together. The NEDSS's Base System core building block is a person-based IDR with data being entered and managed via the web and with the capability for electronic messaging and interchange. The base system is a modular system with a core demographic module (CDM), a Nationally Notifiable Disease module (NNDM), and other specific program area

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modules (PAMs) that, when built, will facilitate the management of disease specific data (e.g., immunizations, lyme disease, bacterial meningitis, and hepatitis). (See Appendix B). In practice, the base system serves as a platform for other modules, eventually encompassing both infectious and non-infectious diseases. In the winter of 2001, CDC piloted the NEDSS Base System in two states and plans a wider beta release in the near future. The first release will support the electronic process involved in notifiable disease surveillance and analysis, functionally replacing the National Electronic Telecommunications System.

THE ROLE OF THE PUBLIC HEALTH LABORATORY

Throughout the century just ended, the responsibilities of public health laboratories expanded well beyond the traditional testing and analysis functions. Today, PHLs continue to provide laboratory support for epidemiological studies and to perform diagnostic tests that may impact the treatment of individual patients. However, they also provide leadership to set laboratory regulations, serve as the standard-of-excellence for local and private laboratory performance, perform specialty testing, provide short- and long-term training nationally and internationally, measure toxic agents to determine the extent of a community's exposure to environmental hazards, and, significantly, are often the first to detect and recognize potential communicable disease threats.

In 1999, APHL identified no fewer than eleven core functions typically assumed by the nation's public health laboratories, ranging from routine disease surveillance to emergency response activities to policy development and communication.² Among these, the capacity for "integrated data management" stands out as being entirely consistent with the principles and activities that fall under NEDSS. According to the APHL report, state public health laboratories "should serve as the focal point for the collection, analysis, and dissemination of laboratory-generated scientific information in support of public health programs." This role involves:

- Capturing clinical laboratory data essential for public health analysis, program planning, and policymaking.
- Maintaining and communicating clinical and public health laboratory data using standardized data formats.
- Assuring the rapid dissemination of laboratory information to help identify, understand and control disease outbreaks.
- Providing a statewide, laboratory-based disease reporting network, with centralized facilities for receipt, storage, retrieval, and analysis of data.
- Participating as a key link in national systems to collect, monitor, and analyze laboratory data (in particular with CDC surveillance systems).
- Serving the data needs of state epidemiologists, other laboratories, and practitioners, to identify trends and "sentinel events," that indicate emerging health problems.

Currently, though, the ability of public health laboratories to participate in electronic data reporting varies greatly throughout the U.S. Once a laboratory achieves this capacity, NEDSS will advance quickly. However, in order to reach this stage, PHLs must be actively involved in state NEDSS activities. For example, state PHL staff in Ohio have participated in all of the state's NEDSS planning activities. Having a seat on Ohio's "Implementation Team" has afforded them the opportunity to provide input into the design of Ohio's Electronic Disease Reporting Surveillance (EDRS) software. In addition, the Ohio PHL has a clearly defined role to play; it performs quality assurance monitoring of all data submitted by public and commercial laboratories using the new EDRS software.³

Many of the nation's PHLs need to develop basic information system capabilities to ensure full participation in NEDSS-related activities.

² "Core Functions and Capabilities of State Public Health Laboratories". 2000. Association of Public Health Laboratories.

³ Personal Communication with McHugh, Will. State of OH, Bureau of Public Health Laboratories.

While only a few state PHLs participate actively in NEDSS today, the majority face barriers. In general, there is convincing evidence that the nation's PHL infrastructure has experienced a loss in capacity in the past few years and is suffering a deficit of training and resources to employ new information technologies effectively. Many of the nation's PHLs need to develop basic information system capabilities to ensure full participation in NEDSS-related activities. For example, PHL data was not included in a recent study documenting the impact of electronic infectious disease reporting in Hawaii.⁴ Why? It was not because the data was unavailable or irrelevant, but because the state PHL lacks a computerized system that would enable direct electronic communication between the state PHL and the state epidemiologist, in essence making public health data unavailable.

The NEDSS initiative provides both opportunity and impetus for PHLs to build information systems or enhance existing systems so that they can provide the laboratory data necessary to help the nation achieve improved public health.

⁴ Effler P., Ching-Lee M., Bogard A., Jeong, M.C. Nekomoto, T., and Jernigan, D. 1999. Statewide system of electronic notifiable disease reporting from clinical laboratories: comparing automated reporting with conventional methods. JAMA. 282(19):1845-50.

PHL PARTICIPATION IN NEDSS

The broad functional scope of public health laboratories is either not generally well understood or not widely recognized. PHL functions go well beyond disease diagnosis and epidemiological support. In fact, PHL expertise extends across a variety of diverse programs including bioterrorism, genetic diseases, environmental quality, radiation monitoring, food safety, newborn screening, and traffic safety (e.g., blood alcohol determinations).

As mentioned above, PHLs have not had ample opportunities or resources to provide input into the development of information systems, yet their input is critical for a number of reasons. They bring to the process:

- A broad knowledge of public health systems not matched by their counterparts in the private sector, as well as an understanding of the ways information travels through those systems to support population-based health objectives.
- A practical knowledge of the data needs of the many public health programs that depend upon routine laboratory support.
- A specialized knowledge of complex laboratory procedures and the salient information that must be recorded to convey complete and accurate information about test results that likely impact public safety.

Overall, PHLs perform several functions that are unique and are crucial to the future development of NEDSS and ultimately to the advancement of public health.

The Scope of Public Health Laboratories Goes Beyond Infectious Diseases, as Does the Scope of NEDSS

Although much of the initial planning for NEDSS has focused on surveillance activities related to infectious disease reporting, the ultimate goal is for NEDSS to accommodate a broad range of public health communications (e.g., environmental health surveillance, injury control, etc.).⁵ As previously mentioned, the public health laboratory interacts with myriad program areas. Precisely because of these extensive interactions, the public health laboratory is an ideal testing ground for the success of NEDSS concepts.

The first release of the NEDSS Base System (described on page 10 and illustrated in Appendix B) will incorporate data modules focused on infectious diseases. Future modules will likely support non-infectious disease programs. The PHLs are in a unique position to inform discussions concerning NEDSS' expansion into these other program areas, to gauge the impact of alternate system models on PHLs, and, ultimately, to facilitate the process of implementing NEDSS standards on a national level. [Systems that should be considered include the STELLAR (Systematic Tracking of Elevated Lead Levels and Remediation), Newborn Screening programs, and the new PulseNet (the National Molecular Subtyping Network for Foodborne Disease Surveillance) and FoodNet (Foodborne Diseases Active Surveillance Network)].

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⁵ The 2nd National Stakeholders' meeting session on "NEDSS Relationship with Other Programs". Apr, 2001.

As NEDSS Migrates Beyond Infectious Diseases, Technical Input from PHLs Will Become Even More Important

The systems architecture for the NEDSS includes an integrated data repository for demographic data and notifiable disease data (Appendix B). Since notifiable disease reporting is overseen by state epidemiologists, a single IDR is reasonable to store notifiable disease data. However, the data flow for non-infectious disease program information varies and may require separate IDRs. For example, metabolic screening tests, including those for PKU and hyperthyroidism, are performed in PHLs that simultaneously report results to primary care physicians and to designated personnel within the state's newborn testing program. Similarly, the childhood lead prevention program may or may not be organized under the office of the state epidemiologist. In any case, lead testing results (positive or negative) must be reported directly to the state lead program, since the statistics associated with the frequency of testing and the location of the population being sampled may also reflect vigor of the surveillance program.

An important conceptual goal of NEDSS is to organize information from multiple sources so that it can be easily exchanged, collected, and analyzed. By adhering to NEDSS identified standards, different state programs should face no technical obstacles that prevent integration or exchange of data between separate IDRs.

The degree of integration and the choice of either a fully integrated system (single IDR) or interoperable separate systems (programmatic IDRs) will vary with the circumstances in each state. Decisions may be influenced by state policy, by data flows, or by organizational structure, and will require cross-program discussions. PHLs are the common link among different program areas (probably the only overarching entity within most SHDs) and will be key players, if not leads, in cross-program discussions at the state level. Throughout this process, the PHLs will also play an important role implementing NEDSS identified standards and developing a common database model so that information can be easily exchanged, collected, and analyzed.

PHLs Perform a Significant Portion of Reportable Disease Testing and Case Reporting Within States and to the CDC. This Data Must Be Captured by NEDSS

By sheer numbers alone, public health laboratories make a critical contribution to disease surveillance in the U.S., processing roughly 40 million reportable disease tests each year.⁶ Clearly, the PHLs perform a significant portion of reportable disease testing compared to private laboratories. Findings from a survey conducted by the Florida State Health Department (FSHD) Bureau of Sexually Transmitted Diseases may be typical of most states (Table 1.). These data show the Florida PHL performs anywhere from 2% to 36% of the 6 notifiable disease tests studied, with private sector laboratories performing the remainder. However, when the percent of positive findings are compared to the percent of tests performed, the relative impact of the PHLs is even more significant ranging from between 30% to 65% of all positive findings. Importantly, these data

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⁶ APHL. 2000.

demonstrate the complementary relationship between public and private laboratories. Moreover, it is reasonable to assume that if data were available for a longer list of notifiable diseases and from more states, it would underscore the fact that data from both public and private laboratories are necessary to eliminate information gaps.

Table 1.
Percent of Total Tests and Percent of Positive Findings
for Six Notifiable Diseases in Florida*

<i>Reportable Disease Test</i>	<i>Percent of Total Tests</i>		<i>Percent of Positive Findings</i>	
	<i>FSHD</i>	<i>Private</i>	<i>FSHD</i>	<i>Private</i>
HIV	17%	83%	30%	70%
West. Blot (HIV)	30%	70%	40%	60%
Chlamydia	33%	67%	56%	44%
Gonorrhea	36%	64%	65%	35%
RPR/VDRL	22%	78%	51%	49%
FTA, IgG, HATP	2%	98%	47%	53%

*Based on a 1999 survey by FSHD Bureau of STD. Information was collected from the Florida PHL and private sector laboratories on the number of reportable disease tests performed and of those, the number of positive findings.

A second study supports this assumption, finding that, in a 1992 survey, primary tuberculosis culture was performed on more than 1,000 specimens per year at fewer than half (46%) of 763 U.S. hospital laboratories versus 86% of state health department mycobacteriology labs.⁷ Just 11% of the surveyed hospital labs identified more than 100 *M. tuberculosis* isolates, compared with 70% of state PHLs. Further, only 15% of the hospitals, compared to 62% of state PHLs, tested more than 100 *M. tuberculosis* isolates for drug susceptibility to determine antibiotic resistance.

PHLs can lead the development of electronic capture of the roughly 40 million public health related laboratory tests they process each year, and thereby close information gaps that sometimes exist among private laboratories, state epidemiologists, and the CDC.

PHLs Can Provide Input into NEDSS to Construct a System that Supports Their Role in the Early Recognition, Confirmation, Control, and Prevention of Infectious Diseases

A surveillance system that exists solely to tabulate individual reportable events is likely to miss unusual cases that do not readily conform to case definitions and are easily obscured in disease background frequencies.

Consider the following example. In January 1996, a microbiologist at the Oregon State Public Health Laboratory noticed a sudden upswing in the number of *Salmonella enterica* serotype Newport isolates being submitted. The

⁷ Tokars JJ, Rudnic JR, Kroc K, Manangan L, Pugliese G, Huebner RE, Chan J, and Jarvis, WR. 1996. U.S. Hospital Mycobacteriology Laboratories: Status and Comparison with State Public Health Department Laboratories. J Clin Microbiol. 34:680-685.

microbiologist recognized this as an unusual finding and alerted state epidemiologists. Health officials soon learned that British Columbia was experiencing a similar outbreak, although no other part of the United States had reported increased Newport isolates. Foodborne illness was suspected.

Epidemiologic investigation suggested that widely distributed food was the source of the problem, eaten mainly by adults, perhaps preferred by women, and usually eaten away from home. The source turned out to be alfalfa sprouts from a 40,000-pound lot of seeds imported from the Netherlands into Kentucky, part of which was shipped to Oregon and British Columbia. With the cooperation of sprout growers, distributors, and regulatory agencies, the seeds and sprouted product were embargoed or recalled.

Although this outbreak resulted in at least 128 cases of salmonellosis (and perhaps hundreds more that went unreported), public health agencies were able to limit human consumption of the seeds as a result of a coordinated public health effort involving well-trained and conscientious public health laboratory staff with the capacity to type and identify unusual pathogens and the savvy to alert appropriate health officials.⁸ If reporting of isolates had been the sole source of information in this instance, the outbreak would have remained undetected longer with a commensurate increase in illness.

Without question, the anthrax bioterrorism acts since September 11, has reminded public health of the front line role of PHLs in recognizing and confirming biological agents and supporting rapid response.

Specialty Testing, Not Performed by the Private Sector, is a Critical Responsibility of State PHLs and an Important Component of Surveillance. Moreover, NEDSS Must Be Able to Accommodate Specialty Test Results

Specialty testing procedures are used to characterize and detect organisms and diseases of public health concern, and even private laboratories rely on PHLs for a number of specialty tests. For example, commercial laboratories often omit routine testing for antibiotic susceptibility on *Salmonella* specimens as a cost-saving measure. As described in the following example, cost savings was the explanation for a large commercial laboratory to drop the routine use of a culture method previously used to recover *E. coli* O157:H7.

A few years ago a national private laboratory, with labs in many states, made a corporate decision to test stools for shiga toxin only if ordered, and to discontinue culturing for *E. coli* O157:H7 in order to cut costs. There was concern among public health officials, locally and nationally, that surveillance of this organism would be difficult if laboratories stopped culturing for it. Because *E. coli* O157:H7 is reportable by law in Oregon, the Oregon State Public Health Laboratory requested that the commercial lab send all shiga toxin positive specimens for *E. coli* O157:H7 culturing. Nationally, public health laboratories are vigilant in filling the potentially dangerous gap created by the corporate

⁸ Adapted with permission from Oregon Health Division, Salmonellosis Outbreak Traced to Alfalfa Sprouts—Oregon and B.C., *CD Summary*, Vol. 45, No. 4, pp. 1-2, © 1996, Center for Disease Prevention and Epidemiology, Oregon Health Division.

decisions of private laboratories that focus on profit, rather than public health, as the benchmark of success.⁹

PHLs and CDC serve as the ultimate sources for determining when specialty testing is important and when new test procedures need to be developed or altered to meet public health needs. The resurgence of tuberculosis¹⁰ and the development of PulseNet are two important examples. The reporting of specialty test results by PHLs through the NEDSS system will be important to strengthen epidemiological surveillance.

PHLs Commonly Employ Molecular Diagnostic Procedures that Result in More Rapid Diagnoses than Standard Testing Used in the Private Sector. As with Specialty Test Results, NEDSS Must Accommodate This Data

It is imperative that laboratories be able to respond rapidly during times of crisis to minimize the adverse consequences of a public health event. Many times, the speed of diagnosis depends on modern molecular diagnostic procedures. PHLs have this capability as illustrated in the following example.

On Friday, January 19, 1996, a man boarded an Amtrak train in Chicago. Because of flooding in southeastern Pennsylvania, he and his fellow passengers transferred to a bus in Pittsburgh and were driven to Washington D.C. On Saturday, January 20, the man boarded another train bound for Miami, Florida. The next day he began coughing up blood, and when the train stopped at a road crossing in Starke, Florida an ambulance brought him to the county hospital. Sputum specimens were collected at the county hospital and sent to a neighboring general hospital. Meanwhile, the patient was transferred to University Medical Center in Jacksonville where additional sputum specimens were submitted to a hospital laboratory. Sputum microscopy revealed numerous acid-fast bacilli, and a specimen was hand-carried to the State PHL for culture and susceptibility testing. By the fourth day after the onset of symptoms, the State PHL reported the detection of *Mycobacterium tuberculosis* using a molecular diagnostic procedure. The rapidity of diagnosis allowed the CDC to start immediate contact investigations on the fellow passengers, who were scattered throughout the country. Two of those in direct contact with the patient had contracted tuberculosis.¹¹

As with specialty testing, it is advantageous to include diagnoses determined by molecular procedures (or by any other methodology not routinely performed by the private sector) in a data repository along with epidemiological data, but distinguishable from standard procedures. The accumulation of this type of data utilizing an integrated NEDSS system will eventually provide valuable information for decision-making.

The reporting of specialty test results by PHLs through the NEDSS system will be important to strengthen epidemiological surveillance.

⁹ Personal Communication. Bob Sokolow. Oregon State Public Health Laboratory.

¹⁰ Tokars JI, Rudnic JR, Kroc K, Manangan L, Pugliese G, Huebner RE, Chan J, and Jarvis, WR. 1996. U.S. Hospital Mycobacteriology Laboratories: Status and Comparison with State Public Health Department Laboratories. J Clin Microbiol. 34:680-685.

¹¹ Salfinger, M., Hale, Y.M., Driscoll, J.R. 1998. Diagnostic tools in tuberculosis: present and future. Respiration. 65:3: 163-170.

The Involvement of PHLs in the Design and Implementation of NEDSS Will Enhance Critical Communications in Times of Crisis as Intended by NEDSS

Direct communication within the SHD, between state PHLs and with the CDC is crucial for national disease surveillance. The published documentation below illustrates PHLs' ability to communicate with each other across state lines, to alert epidemiologists, and to follow through with complete testing.

The original telephone call came from the director of the Colorado Public Health Laboratory to the Nebraska Public Health Laboratory. The director notified his colleague that they were sending over a *Salmonella* isolate that was recovered from a Nebraska resident who had surgery in a Colorado hospital. The *Salmonella* was resistant to multiple antibiotics and was considered to be a probable DT104 isolate, a form of *Salmonella* resistant to more types of antibiotics than any other at that time. After receiving the isolate, the laboratory contacted the state epidemiologist, who initiated an investigation. However, the laboratory drew special attention to the case when the isolate was re-tested and found also to show resistance to third generation cephalosporins, the first specimen ever to do so. Thanks to the re-test and direct communication of the results, this case prompted a national review.^{12 13}

The integration of PHL laboratory communications into each state NEDSS system will enhance rapid information dissemination in times of crisis, as in the above case.

¹² Dunne EF, Fey PD, Kludt P, Reporter R, Mostashari F, Shillam P, Wicklund J, Miller C, Holland B, Stamey K, Barrett TJ, Rasheed JK, Tenover FC, Ribot EM, and Angulo, FJ. 2000. Emergence of domestically acquired ceftriaxone-resistant *Salmonella* infections associated with AmpC beta-lactamase. *JAMA*. 284(24):3151-6.

¹³ Fey PD, Safranek TJ, Rupp ME, Dunne EF, Ribot E, Iwen PC, Bradford PA, Angulo FJ, and Hinrichs, SH. 2000. Ceftriaxone-resistant *salmonella* infection acquired by a child from cattle. *N Engl J Med*. 342 (17):1242-9.

CRITICAL PUBLIC HEALTH LABORATORY QUESTIONS

Health officials expect NEDSS to have a major, positive impact on the continued improvement of the U.S. public health system primarily because of its broad, long-term vision. Precisely because of its broad and inclusive nature, the NEDSS initiative will prompt questions specific to various program areas. Below are several PHL-specific questions, as well as general questions that must be resolved as the development process moves forward.

What is the Relationship Between Public Health Laboratory Information Management (LIM) Systems and NEDSS Systems Architecture?

The operation of a modern laboratory requires the full integration of an information system into the daily functions of the laboratory, as well as the capability to provide a subset of relevant information to public health players outside of the laboratory. For example, PHLs provide services to vector control programs to test for insect-borne viruses, environmental quality programs for air and water testing, law enforcement agencies for blood alcohol testing and forensic procedures, animal control officers and veterinarians to test animals for rabies, as well as hospital infection control specialists for evaluation of nosocomial outbreaks and antibiotic resistance.

Because very few commercial products provide the full range of capabilities needed for public health laboratories, several states have developed customized LIM systems to fill this niche. In addition, a ten-year effort by the CDC has led to the creation of software for a LIM system called “LITS-Plus.” This software is being implemented in several states.

State LIM systems contain some laboratory operational data unimportant for reporting and surveillance. Nonetheless, it will be extremely beneficial to NEDSS to have a portion of the existing laboratory information electronically linked to surveillance and reporting systems. It is very important that these electronically shared data are standardized and share the same vocabularies. The prominent examples of data that will be shared between state LIM systems and NEDSS are the fields and vocabularies used to describe laboratory tests and test results and the core demographic data fields. Additionally, it is extremely important that state LIM systems be interoperable with NEDSS and the relationship between LIM system and NEDSS be clearly defined.

How Will NEDSS Address the Different Methods of Communication Between the CDC and State Health Departments?

Alongside the patchwork of discrete information and surveillance systems that NEDSS will replace are myriad discrete routes of communication between CDC and SHDs. Currently, for example, state PHLs frequently receive laboratory reports directly from CDC laboratories, bypassing state epidemiologists and program directors. Similarly, state PHL reports are often routed directly to the CDC, again bypassing state epidemiologists and program directors. Further complicating the flow of information is the existence of both patient-oriented and

surveillance-oriented communication channels between the state health agency and the CDC. And finally, there are lab-to-lab connections (e.g., PHLIS, PulseNet, STELLAR, STD, etc). Some of these lab-to-lab reports go from laboratory staff to state epidemiologists and program directors and then to CDC, and some are routed directly to the CDC. Working with NEDSS to establish the optimal flow of communications will be important to develop a more cohesive flow of information. NEDSS suggests a way to implement a standing architecture for secure data exchange using the Internet. With such an infrastructure in place, data exchange internal to states, between states, and among states and other public health partners will be possible.

How Will the Use of Different Technologies by Various Laboratories Be Incorporated into the NEDSS Reporting Systems?

Because testing technologies have a profound impact on the identification of infectious agents, NEDSS must somehow build into the data reporting system the capacity to capture this information. The PHLs have the expertise to help develop this capacity by determining the exact laboratory information necessary for a complete and accurate interpretation of test results (including test limitations). Over the long run, PHL input will be necessary to assure that data fields evolve with testing technologies (e.g., there will be a need to modify documentation fields as new technologies develop and to modify the database when changes in test procedures or reagents may influence the interpretation of test results). The availability or non-availability of accurate laboratory data greatly influences disease reporting and epidemiological analysis of disease trends.

How Will NEDSS Address Issues Related to Different Coding Systems?

The NEDSS architecture calls for the use of standardized national nomenclature to facilitate information exchange. However, automation of standardized nomenclature in turn requires the use of common codes so that databases may be filtered, processed, and updated. NEDSS has endorsed two coding systems for laboratory test names and test results—LOINC and SNOMED—both of which are slowly gaining acceptance as the coding systems for HL7 messages, including some large commercial and hospital laboratories. (HL7 is the NEDSS standard for electronic messaging. CDC's work in this area predates the NEDSS initiative.^{14 15})

Although LOINC and SNOMED have also been adopted as standards in the public health sector, much work remains in at least two major areas: usage by the private sector and granularity for public health applications. Mapping (linking

¹⁴ Centers for Disease Control and Prevention. Electronic Reporting of Laboratory Information for Public Health: Summary of Meeting Proceedings. January 7-8, 1999. Atlanta Ga.: Centers for Disease Prevention; 2000. (Available from CDC/NCID).

¹⁵ Centers for Disease Control and Prevention. Electronic Reporting of Laboratory Information for Public Health: Meeting Report and Recommendations. November 23, 1997. Atlanta Ga.: Centers for Disease Control and Prevention; 2000. (Available from CDC/NCID).

codes to nomenclature) is inherent in the use of standardized codes and, as the use of standardized coding systems increases nationally, so too will the need for more sophisticated mapping tools. For example, the Dwyer Tables¹⁶, a spreadsheet that associates reportable findings with LOINC and SNOMED codes, greatly facilitates the identification of conditions and tests. But, the demand for updating and expanding the Dwyer Tables or developing other mapping tables (and providing a process for change and maintenance) is growing. For several infectious organisms (i.e., Salmonella) public health laboratories provide strain or typing data that is not currently covered by SNOMED codes. To address this need, the PHLs and APHL can contribute significantly towards updating and maintaining the coding standards related to laboratory information for the Dwyer Tables. SNOMED, in particular, is in the area of PHLs expertise.

Also, local codes used in the laboratory must be mapped to LOINC and SNOMED before an HL7 message can be formed. While there are mapping tools available, better tools are needed and a standard should be developed for use in laboratory information systems.

Finally, alternate coding systems, such as ICD9 and CPT, are widely used by Medicaid, private laboratories, and insurance systems. Since LOINC and SNOMED have not received widespread acceptance in the private sector, use of these multiple coding systems is a problem. Laboratories must utilize these additional systems in order to obtain reimbursement and they should be included in NEDSS data collection activities.

Will NEDSS Address Issues Related to the PHL's Medicaid Billing Process?

PHLs routinely bill state Medicaid systems for services for eligible patients. In order to do so, however, they must comply with strict regulations governing not only what data is reported to Medicaid, but also how that data is formatted. The administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) require the adoption of national standards for electronic transmission of health data (currently for administrative/financial data only), which includes electronic Medicaid billing processes. Other billing requirements (such as documentation of tests) may also influence data collection. PHLs have the expertise to assist the CDC in the design of a system that will capture important information created by the billing process.

How Will NEDSS Handle Differences in Laboratory Data, for Example CLIA Regulated Data and Non-CLIA Regulated Data?

The Clinical Laboratory Improvement Amendments of 1988 (CLIA'88) govern the performance of laboratory tests that will be linked to a patient, regardless of the purpose for testing, i.e., for diagnosis, prevention, assessment and even epidemiologic studies and research. Consequently, most test procedures and criteria for interpretation are comparable in laboratories that meet CLIA

¹⁶ <http://www.regenstrief.org/loinc/>

regulations. However, an exception exists when there is not a link back to a patient and CLIA regulations do not apply. This exception occurs in some epidemiological and research studies, and the resulting data may or may not be comparable to data for similar tests subject to CLIA. Different test protocols may have been used and the criteria used to interpret test results may have been different. To further complicate matters, some states have additional laboratory performance requirements beyond CLIA that may influence laboratory data. There may be a need to develop guidelines or recommendations to restrict the kind of laboratory data that will be included in a NEDSS integrated data repository so that national laboratory data are comparable. The expertise of the PHLs will be valuable to address this issue as the integrated data repository is designed and implemented.

How Can Funding Mechanisms Be Better Structured to Maximize PHL Participation in NEDSS Activities?

Funding for the development of information technology capacity in PHLs is almost nonexistent. This PHL funding gap is the result of the current structure used to distribute and administer federal funds to state health programs. This structure utilizes a single principal investigator within the state health agency who is responsible for coordinating all aspects of the grant. Since the involvement of laboratory personnel in this process is encouraged, but not required, the representation of PHLs is low. As a direct result of this system, federal funding streams, for the most part, bypass the PHLs. Consequently, funding for new information technologies has not been available in many PHLs, which makes participation in the implementation of NEDSS architectural elements nearly impossible (e.g., electronic laboratory reporting).

Even the *Epidemiology and Laboratory Capacity* (ELC) grants rarely have principal investigators who are laboratorians, despite the fact that these grants are intended to build PHL capacity. (In this case, much of the problem lies with the nonspecific terminology used for PHLs. “Epidemiology” readily equates to a public entity, while “laboratory,” unless otherwise specified as a public health laboratory, does not.) Since ELC grants are a primary mechanism for the distribution of NEDSS funds, continuation of the current structure and budget development process is unlikely to provide the funds to maximize PHL participation in state NEDSS activities. In contrast, the funding mechanisms used for bioterrorism and West Nile virus programs define specific laboratory components, thus ensuring active PHL participation. In the future, it is important that CDC be explicit in the guidance for NEDSS grant applications and specifically identify state PHLs activities that meet grant requirements.

RECOMMENDATIONS AND CONCLUSION

To maximize the efficiency and usefulness of NEDSS and to address the specific issues outlined above, APHL's MIS Committee, with full APHL support, recommends that the CDC take the following actions:

- Convene in partnership with APHL a national meeting in 2002 to discuss and plan the incorporation of public and private laboratory information into NEDSS; to increase the ability of PHL to electronically report laboratory test results; to define the relationship between LIM systems and NEDSS; to address the unanswered questions and to propose concrete projects to strengthen the participation of laboratories (public and private) in NEDSS. The meeting should include PHL directors, CDC's senior advisor for CDC/integrated health information systems, NEDSS staff (CDC/state), representatives from commercial laboratories, state epidemiologists, other appropriate state health officials and representatives from the partner organizations.
- Implement the following steps to close the gap in PHL participation in NEDSS:
 - Make specific provisions for the inclusion of PHLs in the next phase of NEDSS design and implementation grants, especially in the areas of bioterrorism, newborn and child health testing, lead testing, environmental sampling, and water quality management.
 - Identify a mechanism to fund PHLs directly to develop electronic laboratory reporting (NEDSS development element # 2, i.e., to "accept, route and process electronic HL7 messages containing laboratory and clinical content.")
 - Encourage interaction between PHLs and private sector laboratories by funding collaborative projects on electronic data interchange.
 - Work with APHL to document the relationship between LIM systems and NEDSS to ensure that state LIM systems are developed according to NEDSS standards.
 - Establish a process for laboratory direction of laboratory specific coding tables for SNOMED (i.e., infectious organisms).

The anthrax bioterrorism events have significantly increased awareness of the critical role PHLs play in protecting the health of our nation at every level.

State public health laboratories directly impact virtually every facet of public health. The anthrax bioterrorism events have significantly increased awareness of the critical role PHLs play in protecting the health of our nation at every level. As documented here, PHLs are strongly committed to advancing public health and strongly committed to utilizing new information technologies. Herein is the impetus for this document. "Advancing NEDSS" has expressed the enthusiasm of PHLs for active partnering with NEDSS, explained the synergy between PHLs and NEDSS, defined the role of PHLs, and identified PHL functions that are important for the advancement of NEDSS. APHL firmly believes that CDC's action on the recommendations will increase participation of PHLs, will greatly benefit NEDSS, will improve rapid response to bioterrorism events, and ultimately move "e-public health" forward.

APPENDIX A

NEDSS Overview

This overview provides text bullets that succinctly summarize key features of NEDSS. **

NEDSS

- The long-term vision for NEDSS is an electronic information system that automatically gathers health-related data from myriad sources on a real-time basis, facilitating our ability to monitor the health of communities, perform ongoing analysis of trends, detect emerging public health problems, and use information as the basis for public health actions and policies.
- NEDSS will ensure that surveillance data is shared appropriately; that consistent, high quality data is accumulated; that users familiar with one part of the system can easily use another; and that software and expertise can be easily shared across programs. NEDSS will also advance secure methods for reporting data.
- NEDSS is a public health initiative that provides a standards-based, integrated approach to disease surveillance and connects public health surveillance to the burgeoning clinical information systems infrastructure.
- NEDSS is not only a standard-based approach, but also has a modular architectural framework.
- NEDSS identifies standards focused on systems architecture, data standards, secure data transfer, common user interface, and tools for interpretation, analysis, and dissemination of data.
- NEDSS includes an Internet-presentable infrastructure for data accumulation and sharing built on industry standards, and facilitates policy-level agreements on data access, burden reduction, and protection of confidentiality.
- NEDSS is not a single monolithic application.
- NEDSS is composed of complementary electronic information systems.

NEDSS Base System

- The NEDSS Base System serves as a starting point for states interested in NEDSS identified standards and technologies to support the electronic process involved in notifiable disease surveillance and analysis. It will provide the functionality currently supported by the National Electronic Telecommunications System for Surveillance (NETSS)—which it will replace—as well as several other existing systems.
- The NEDSS Base System is *not* intended to represent the complete NEDSS solution, but provides the foundation upon which data collection and processing functions can be built to meet specific state and program needs.

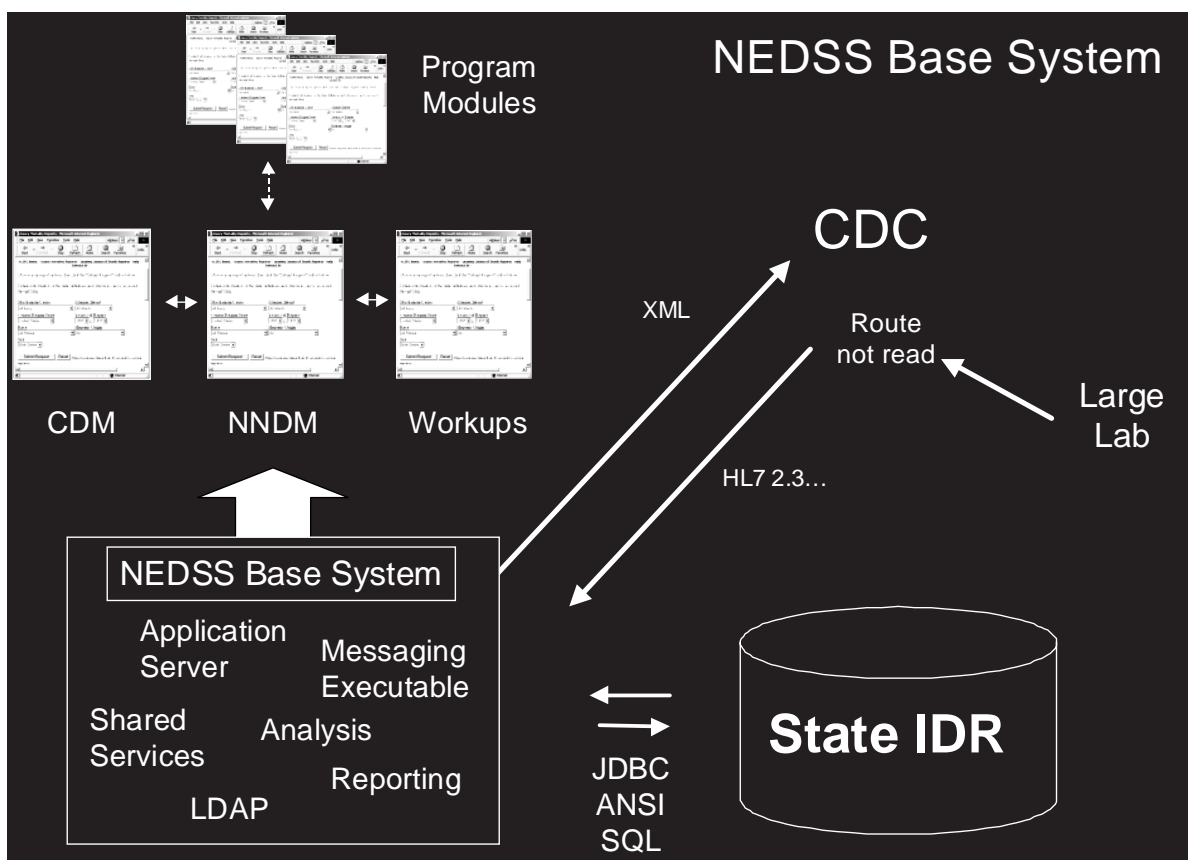
- This foundation includes discrete modules that can be used for data entry and management of core demographic and notifiable disease data.
- The NEDSS Base System is intended for use by state health departments for communicable disease surveillance. Future modules will likely support the content and functionality relevant to other programs (e.g., chronic disease or environmental health programs).
- Three major functions are: (1) data entry via the Web; (2) electronic interchange of laboratory and other standards-based data; and (3) data storage and maintenance.
- The architectural components are: Web-based modules, Web application server (J2EE compliant), Integrated Data Repository (IDR, to be supplied by the state), a messaging software tool (E-link executable), security (using existing state infrastructure or a CDC provided, intranet-oriented authentication and authorization system), data analysis functionality (SAS software for analysis, and SAS Data flux software for deduplication and data cleaning).

**These bullets were paraphrased or extracted from CDC publications (such as distributed materials at the NEDSS Stakeholders' meetings) and from Power Point® presentations made available by CDC NEDSS staff at various public meetings.

APPENDIX B

Architecture for the NEDSS Base System

The major components of the base system are diagrammed below. These components will be structured to support 1) data entry via Web-based screens, 2) an application server (J2EE compliant) that will support the functionality of the Web-based screens, and 3) storage of demographic and notifiable disease data in an integrated database (e.g., IDR). Tools will also be provided for messaging between states and the CDC (electronic data interchange), data analysis (e.g., SAS), and authentication/security functions.



APPENDIX C

Glossary / Acronyms / Websites

This glossary contains terms that may or may not have been used in this document. All, however, are terms that may be encountered in other materials related to NEDSS or information technology, in general.

AMIA: The American Medical Informatics Association. Web site: www.amia.org

ANSI: The American National Standards Institute (ANSI) is a voluntary standards organization that coordinates national standards in the United States and is the U.S. member body to the International Organization for Standards (ISO). ANSI accredits standards committees and provides an open forum for interested parties to identify, plan, and agree on standards; it does not itself develop standards. Standards are developed by Standards Development Organizations (SDOs). Web site: www.ansi.org

APHL: The Association of Public Health Laboratories. Web site: www.aphl.org

Application Server: A framework of software components that provides services that are used by software applications. (e.g., Windows® applications, such as Microsoft Word®, use services provided by the Windows® application server).

Application: A computer software program. Types of applications include word processor programs, spreadsheet programs, database management systems, and presentation applications.

Architecture: The high-level, abstract, blueprint that shows what the components of a software system (e.g., NEDSS) are and how they fit together.

ASTHO: The Association of State and Territorial Health Officials. Web site: www.astho.org

CDM: Core Demographic Module. The data elements in the CDM of the NEDSS correspond to data elements currently used by CDC's National Electronic Telecommunications Surveillance System (NETSS) or to data elements identified in NEDSS documents.

Client/Server: Client/server computer architecture refers to a system of networked computers in which the processing is shared between a central machine (the server) and the desktop computer (the client).

CSTE: Council of State and Territorial Epidemiologists. Web site: www.cste.org.

Data Model: A framework for the development of a new or enhanced application. The purpose of data modeling is to develop an accurate model, or graphical representation, of the client's information needs and business processes.

Data Repository and Integrated Data Repository (IDR): One or more databases of information. An integrated repository stores standardized data and allows for complete interchange and interoperability. An integrated data repository would, for example, allow the data from one public health program to be cross-linked and analyzed in association with another public health program.

Data warehouse: A computer industry term that refers to a data repository that accumulates data from many different systems. Data warehouses do not necessarily employ shared data, which can limit their utility. Data warehouses are also intended for data analysis needs only. They are not usually intended for “live” data entry or transactions.

Dwyer Tables: The common name for tables that link LOINC and SNOMED codes with the names of the notifiable diseases to which they correspond.

Electronic Data Interchange (EDI): A standard format for exchanging business data. An EDI message contains a string of data elements, each of which represents a singular fact, such as price, product model number, and so forth, separated by delimiters (a character that identifies the beginning and end of a character string). The entire string is called a data segment.

Electronic Laboratory-Based Reporting (ELR): Electronic transmission of data of public health importance from public health laboratories, clinical laboratories, and commercial laboratories to public health agencies. Ideally, data transmitted by ELR is automated and uses standard codes for tests and results to facilitate timely and complete reporting.

Extensible Markup Language (XML): A specification developed by the World Wide Web Consortium. XML is designed especially for Web documents. It allows designers to create their own customized tags, enabling the definition, transmission, validation, and interpretation of data between applications and organizations. Web site: www.w3.org/xml/

FoodNet: The acronym for the Foodborne Diseases Active Surveillance Network. FoodNet is an active laboratory-based surveillance system with over 300 clinical laboratories that test stool samples in nine participating sites.

Health Insurance Portability and Accountability Act (HIPAA): The administrative simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) are intended to reduce the costs and administrative burdens of health care by making possible the standardized, electronic transmission of many administrative and financial transactions that are currently carried out on paper. Web site: www.aspe.hhs.gov/admsimp

Health Level 7 (HL7): HL7 is an accredited, nationally recognized organization that develops standards for the exchange and processing of data that supports health care management, delivery, and evaluation. HL7 is not a commercial software or data transfer package, but a defined set of rules for sending simple text characters in groups that represent patient identifiers, clinician identifiers, laboratory test information, test results, and other clinical and administrative data. The standard allows communication between different types of information systems. Web site: www.hl7.org

ICD-9: International Classification of Disease, 9th revision. Originally published by the World Health Organization (WHO). George Hripcsak's ICD-9 code lookup is at www.mcis.duke.edu/standards/termcode/icd9/index.

Integrated Database: One database, shared enterprise-wide.

Interoperability: The ability of software from multiple vendors to work together, communicate, and share resources using a common set of protocols.

JDBC: Java Data Base Connectivity. A standard that allows Java programs to interact with any SQL compliant database.

Laboratory Information Management (LIM) System: An electronic information system that manages daily laboratory functions and provides data to state programs, private health providers, local health officials and federal agencies.

LDAP: Lightweight Directory Access Protocol. A standard for computer directory services. It is a vendor-independent, open, network protocol standard. It is platform independent and supports interoperability in the same fashion as a Simple Mail Transport Protocol (SMTP).

Logical Observations, Identifiers, Names, and Codes (LOINC): The LOINC database provides a set of universal names and codes to identify laboratory and clinical observations. It facilitates the exchange and pooling of clinical laboratory results (such as blood hemoglobin or serum potassium) for clinical care, outcomes management, and research. Web site: www.regenstrief.org/loinc/loinc.

NACCHO: The National Association of County and City Health Officials. Web site: www.naccho.org.

NAHDO: The National Association of Health Data Organizations. Web site: www.nahdo.org.

NAPHSIS: The National Association of Public Health Statistics and Information Systems. Web site: www.naphsis.org.

NEDSS: The National Electronic Disease Surveillance System, a CDC initiative. Web site: www.cdc.gov/od/hissb/docs.

NETSS: National Electronic Telecommunications Surveillance System. A CDC surveillance system for notifiable diseases that is being replaced by the NEDSS.

NNDM: The acronym used by NEDSS for the National Notifiable Disease Module.

PAM: The acronym used by the NEDSS for Program Area Modules.

PHDSC: The Public Health Data Standards Consortium. Web site: www.cdc.gov/nchs/otheract/phdsc/phdsc

PHLIS: The acronym for CDC's **P**ublic **H**ealth **L**aboratory **I**nformation **S**ystem. PHLIS is an electronic reporting system for foodborne and diarrheal diseases (e.g., Salmonella, Shigella, E.coli O157:H7) used by state PHL directors and epidemiologists for reporting to CDC/NCID.

Process Model: A framework describing the activities and functions of an organization. Processes in this type of model are often defined in terms of inputs and outputs. Process models often accompany data models (which present a static view of organizational data).

Public Health Conceptual Data Model (PHCDM): A high-level conceptual model, developed as part of the CDC NEDSS initiative, which provides the foundation for standardization of public health data collection, management, transmission, analysis, and dissemination. Web site: www.cdc.gov/od/hissb.

PulseNet: A national network of public health laboratories that perform DNA "fingerprinting" on bacteria that may be foodborne. Fingerprint patterns are entered into an electronic database at the local and state levels and transmitted to CDC where they are filed in a central computer.

Relational Database: A data that represents the data to users as the contents of one or more tables. These tables are made up of columns and rows; tables are related through one or more columns.

SENSOR: The acronym for **S**entinel **E**vent **N**otification **S**ystem for **O**ccupational **R**isks. SENSOR's underlying goal is the prevention of occupational disease and injury. It is one of the major CDC/NIOSH surveillance programs.

SilverStream: An application server based on J2EE that allows enterprises to build and deploy complex EJB (**E**nterprise **J**ava **B**ean) applications with rich HTML and Java interfaces and broad access to enterprise data sources. Web site: www.silverstream.com/website/staticpages/home.

SNOMED: The acronym for **S**ystematized **N**omenclature **o**f **H**uman and **V**eterinary **M**edicine. SNOMED is a proprietary standardized medical nomenclature that is used in electronic laboratory-based reporting to code test results. SNOMED is embedded within or enabled by a broad range of systems that include electronic medical records systems, anatomic pathology laboratory systems, clinical pathology laboratory systems, data warehousing and decision support systems. Web site: www.snomed.org.

SQL: The acronym for **S**tructured **Q**uery **L**anguage, a standard language for requesting information from a database.

STD: Sexually Transmitted Diseases.

STELLAR: The acronym for **S**ystematic **T**racking of **E**levated **L**ead **L**evels **A**nd **R**emediation. STELLAR is a software application for state and local lead poisoning prevention programs that provides an electronic means to address the data received from laboratories, providers, clinics, and case management professionals.

Web Browser: A computer program that allows a user to access the hypertext and multimedia information on the World Wide Web. Examples include Netscape Navigator® and Internet Explorer®.

Workflow: Computer-automated tasks and communications for organizing work. When implemented, workflow expedites many manual steps. For example, when a person is hired, workflow can notify appropriate human resources staff and send information on orientation and benefits to the new employee.

Workups: The accumulated collection of observations, notifications, interventions, and referrals made by public health workers on a given individual for one or more conditions. It is synonymous with the term *case workup*, but is used to cover a broader range of conditions than just those covered by case definitions.

World Wide Web Consortium (W3C): An industry consortium that promotes standards for the evolution of the Web and interoperability among WWW products. Web site: www.w3.org.

APPENDIX D

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